Working Party Morbidity and Mortality
Task Force on Major and Chronic Diseases

Building a European System of Information
on Major and Chronic Diseases

Antoni Montserrat Moliner
Directorate C – Public Health and Risk Assessment
Unit C 2 - Health Information
The Morbidity and Mortality Working Party (MMWP)

- To provide a forum for discussion and exchange of views and experience on information and knowledge in the fields of Morbidity and Mortality;
- The MMWP will serve as an expert group to advise on information and knowledge for monitoring Community policies and other initiatives in the field of morbidity and mortality;
- The concept of health information and knowledge should be understood for the major diseases as the collection, processing, sharing and analysis of objective, reliable, compatible and comparable data on diseases affecting human health;
- The MMWP will assist the Commission in the development and co-ordination of the Health Information System, completing the technical and scientific background work for the establishment of major disease indicators and other information needs;
- To contribute, in close coordination with Eurostat, to collect comparable morbidity data at EU level with a final objective: to compare what is really comparable;
- To contribute to the inventory and to the development of a comprehensive and comparable health measurement for health surveys in the EU and the Member States contributing to develop modules for surveys (HIS and HES).
The Task Force on Major and Chronic Diseases (TFMCD)

- The TFMCD will assist the Commission to set up priorities in the areas on major and chronic diseases;
- To advise the Commission in the analysis of developments in the information for specific diseases;
- To give an opinion about necessary actions for improvement in the field of health information on diseases;
- To give suggestions for modules on disease specific information to be implemented in the European Health Survey System
Health information systems in DG SANCO

Our legal basis

- Decision No 1786/2002/EC of the European Parliament and of the Council of 23 September 2002 adopting a programme of Community action in the field of public health (2003-2008), envisages the creation of a comprehensive and sustainable health monitoring and information system, building on work done in previous Community public health programmes, work in the Statistical Programme and other Community programmes such as the research programme, and taking into account the activities of related international organisations.

- Communication to the Commission: Community action in the field of public health (2003 to 2008), Work plan 2005, including the annual work programme for grants. A mid-term evaluation shall be carried out after the first three years of the programme’s lifecycle to provide information on process efficiency, outputs and outcomes plus an analysis on the success rate.
Health information systems in DG SANCO

Some objectives of the Public Health Program

- Increasing life expectancy without disability or sickness
- Dealing with health threats particularly communicable diseases and bioterrorism
- Reducing differences in health status and health outcomes – tackling inequalities in health
- Attention to major burdens of disease
- Addressing health determinants through promotion and prevention (tobacco, nutrition and alcohol)
- Health protection in all EU policies and activities
- The citizens’ dimension and equal access to information
- Needs of the new EU Member States
Health information systems in DG SANCO

In the field of morbidity and mortality information, priority will be given in DG SANCO on 2005 and following years to:

- To improve dissemination and knowledge on existing EU morbidity inventories;
- To develop an European System of Information on Major and Chronic Diseases;
- To improve existing networks and databases in the field of Rare Diseases;
- To support the development of the European Health Survey System;
- Analysis of specific consequences of events leading to unforeseen levels of mortality, consequences of the enlargement, certification procedures and improvements in the collection of data in the European Short List of 65 causes of death
Health information systems in DG SANCO

These systems should be able to ensure:

- The availability of health information and knowledge: accessible information to policy-makers, public health experts, researchers and the public at large regarding public health problems,
- Data Quality: comparable, harmonized, valid, reliable, timely information regarding public health issues,
- Relevance: information linked to public health concerns,
- Efficiency: reasonable cost per high quality and relevant information
Health information systems in DG SANCO

The main components of the European Union Health Information and Knowledge System are listed as follows:

- The European Community Health Indicators (ECHI) system at national level
- The System of Regional Indicators on Health (ISARE) at sub-national level
- A system of health indicators in urban areas
- A system of sources and inventories on health information
- A system of information and knowledge on major and chronic diseases
- A system of networks and databases in the field of Rare Diseases
- The Epidemiological Surveillance and control of Communicable Diseases Network
- A system of information on life styles and other health determinants
- The European Community Environment and Health Information System (ECOEHIS)
- The DG SANCO Injury database (Euro-IDB)
- The European Health Survey System (EHSS)
- A Hospital Activity and Resources Information System
- Performance assessment of health care institutions to asses and compare quality strategies
- The System of Health Accounts (SHA)
- A system of information on patients mobility
- A system of information on health professionals mobility
- The Haemovigilance system
Health information systems in DG SANCO

The objective is that the information should be collected for these main components:

- on a routine register or survey basis when possible (with Eurostat as the main EU provider);
- on the basis of DG SANCO established systems (ECOEHIS, ISS, communicable diseases);
- from Community Public Health projects on a non routine basis;
- on the basis of future modules from the Eurostat / DG SANCO European Health Survey System (EHSS) for other health status indicators.
Inventories of morbidity data under HMP

- The European Union Morbidity Inventory Project (EUMIP)
- Euro-Med-Data (EMD)
- IRIDE (Inventory of Resources for Infectious Diseases in Europe)
- ORPHANET (Rare diseases)
- Hospital Data Project
Inventories of morbidity data under HMP

Other complementary needs:

- To support the improvement of dissemination and knowledge on the existing EU morbidity inventories between experts and general public.

- To update and expand the European Union Morbidity Inventory Project (EUMIP). The project has stopped in 2000 and additional and new work (especially in the IT framework to ensure accessibility and sustainability of the project) is necessary.

- To create an inventory database giving a special attention to sources on information on primary care (GP’s databases, Primary Units and others). The Health monitoring in sentinel practice networks (Phase 1) Project from NIVEL (The Netherlands) has produced a very good theoretical framework for such a project.

- To explore the feasibility of inventorying potential sources of data in the residential and nursing homes care sector. The data on morbidity and polimorbidity in aged institutionalised populations are not captured by traditional instruments as health surveys, hospital discharges or others.
A priority area in 2005: the ECHI indicators list

- The HMP project ECHI *Recommended set of first phase core indicators* contents some indicators in the field of major diseases.
- With NewCronos, HMP Projects and other international sources, it is possible to complete only partially these information requirements.
- The aim of the projects to be supported in the future by DG SANCO is to contribute to fill these gaps.

First step:
- Former projects supported by DG SANCO have produced a very good basis of knowledge on indicators and methodologies for working in different diseases groups and conditions.

Second step:
- *Operationality and sustainability* in a continuous perspective of a European System of Information on Major Diseases becomes the priority.
- Implementing in an operational way in order to be able to answer the questions: How many people suffers in Europe of such diseases or conditions? Which is the distribution of these people by sex or age? etc.
- To orient activities to a real implementation of information in a usable way combining existing sources (or developing when necessary).
- Final goal: implementation on a free basis of all this data in the DG SANCO web site and, in a later phase, in the EU Health Portal.
Combining sources of information

Specific problems in EU morbidity data

- To build EU data is not to construct a table with national data from national sources
- Needs inventories and analysis source by source
- Needs harmonisation and methodological description
- Needs a lot of ‘footnotes’ (not be afraid about)
- The objective is to compare what is really comparable
Combining sources of information

Sources used in the EC for information on morbidity

- Statutory notifications (communicable diseases)
- Comparable survey data (HES, HIS, Eurobarometer)
- Integration of survey data with other sources
- Disease-specific registers
- Hospital discharges
- Sources combining registers and hospital samples
- Epidemiological studies (HMP, BIOMED, Rare Diseases, ...)
- Patients organisations data
Combining sources of information

Communicable diseases (also difficult to compare)

- **Statutory Notification Systems (SNS)**
  - notification system varies from one institution (A, IRL, E&Wales, FIN, CH) to four (NL)
  - various intermediate level sending information to various national level institutions (D, I, P)
  - number of diseases and pathogens subject to statutory notification ranges from 22 in France to 80 in Finland

- **Non-Statutory Surveillance Systems (NSSS)**
  - NSSS are established for practical purposes, they are not established with specific legislation
  - number of NSSS in individual EU countries ranges from 1 to 20 (except L and N)

- **Central laboratory reports**
  - In seven countries [N, S, FIN, B, DK, CH], laboratories also serve as notifiers, though their roles in the notification system vary by country.
Combining sources of information in HMP Projects

- a) Information and data combining registers and hospital samples
  - IARC database (EUCAN)

- b) Information from Health Monitoring Programme projects combining sources
  - EUROCHIP (European Cancer Health Indicators Project)
  - EUROCISS (Cardiovascular Indicators Surveillance Set)
  - Indicators for Monitoring Musculoskeletal Conditions
  - Mental health indicators in EU
  - PERISTAT Indicators for monitoring and evaluating perinatal health in Europe
  - REPROSTAT (Reproductive health indicators in the EU)

- c) Information from BIOMED or R&D using epidemiological studies
  - EuroParkinson
  - Outcome of Depression in Europe (ODIN)
  - DEPRES (Depression Research in European Society)
  - European Study of the Epidemiology of Mental Disorders (ESEMeD)
Combining sources of information in HMP Projects

- d) Information using registers
  - EUROCAT
  - IARC database (ENCR)

- e) Information using HES data
  - European Community Respiratory Health Survey (ECRHS)
  - WHO MONICA Project
  - European Vertebral Osteoporosis Study (EVOS)

- f) Information using Hospital Discharges Data
  - Hospital Data Project

- f) Patients organisations data
  - Alzheimer Europe
  - ORPHANET/EURORDIS
Combining sources of information in HMP Projects

<table>
<thead>
<tr>
<th></th>
<th>Care use</th>
<th>Surveys</th>
<th>Registries</th>
<th>Insurance</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Back pain</td>
<td>PC, Phys 2</td>
<td>(but) 1</td>
<td>-</td>
<td>Sick leave 3</td>
<td>-</td>
</tr>
<tr>
<td>Osteoarthritis</td>
<td>PC 1</td>
<td>(but) 2</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Depression</td>
<td>PC 2</td>
<td>CIDI 1</td>
<td>-</td>
<td>Sick leave 3</td>
<td>Hospital discharges 4</td>
</tr>
<tr>
<td>Dementia</td>
<td>PC 1</td>
<td>HES 2</td>
<td>?</td>
<td>?</td>
<td>Patients data 3</td>
</tr>
</tbody>
</table>

- This matrix is defined as Asymmetric (different by Member State and different by disease) and Dynamic (it could change over the time and the importance of the sources). Some current projects in the HMP framework could complement this work. The importance of the linkage of sources was also stressed by the experts. Gradually the Matrix could also be completed with data.

- A report from the ONS (Office for National Statistics – UK) about the feasibility of this matrix is expected soon and Eurostat action to test the feasibility of the matrix could be also launched soon.
Diseases information in DG SANCO web

‘Morbidity / Diseases sheets’ in the web site:

- **Cancer**: EUROCHIP, CAMON, EUCAN database, an explanatory link with IARC, an explanatory link with data in NewCronos (mortality, hospital diagnosis, prevention), the Eurobarometer data (prevention), other sources suggested by the WPMM;

- **Musculo-skeletal diseases**: ‘Indicators for Monitoring Musculo-skeletal Conditions’ Project, EVOS, MEDOS, an explanatory link with the Dublin Foundation, an explanatory link with da in NewCronos, the SIF’s about LFS ad modules on work-health related diseases, the Eurobarometer data (prevention), other sources suggested by the WPMM;

- **Cardio-vascular diseases**: EUROCISS, MONICA, a link with the main CV surveys, CARDS project, an explanatory link with da in NewCronos, the Eurobarometer data (prevention), other sources suggested by the WPMM;

- **Diabetes**: EUDIP, the former EURODIAB, the WHO International Diabetes Institute, an explanatory link with da in NewCronos, other sources suggested by the WPMM.

- When available: **COPD** (Chronic Obstructive Pulmonary Diseases).
Major diseases not covered by HMP or PHP projects

The draft Work Plan 2005 contains some concrete recommendations to improve morbidity and mortality information:

- Special attention will be given to areas of disease information, not yet covered, including inventories of sources and definition of indicators, according to the ECHI strategy, for: haematological diseases, immunological disorders, allergies except asthma, genito-urinary diseases and nephrology disorders, gastroenterological diseases, endocrinological diseases, ear-nose and throat disorders, ophthalmology disorders and dermatology diseases as well as diseases related to environmental factors.

- Special attention should also be given to information and definition of indicators on neurodegenerative (and, in general, brain diseases) relating to prevalence, treatments, risk factors, risk reduction strategies, cost of illness and social support as well as what constitutes a “healthy brain lifestyle”. That includes Alzheimer and other dementias, Parkinson, Multiple Sclerosis, Epilepsy, and Amyotrophic lateral sclerosis as well as stroke, headache disorders and chronic pain.
Major diseases not covered by HMP or PHP projects

- The ECHI long list (see also Annex 5 of the ECHI-1 final report) covers exhaustively additional needs. The criteria are to work with larger numbers of diseases. Too much focus on many and very detailed diseases for the sake of burden to health care will deviate focus from public health and prevention.

- Previous Work Plans have paid not enough attention to children with the exception of neonates. There are different patterns of major and chronic diseases manifesting in childhood, including asthma, overweight and obesity, and childhood diabetes. Measurement of these chronic diseases is admittedly not easy but the impact of significant illness in childhood (such as that requiring six months or more convalescence), whether a chronic disease or not, has a significant immediate impact on family and society as well as the individual child, but secondly potentially has an impact on the child for the rest of their adult life.

- In the perspective of the DG SANCO Work Plan 2006 proposals on other diseases groups will be
Mortality

The future assessment actions on mortality in the WPMM will focus on

- Projects are encouraged to look at morbidity and mortality data together producing like this an important added value.

- Analysis of potential effects and specific consequences of events leading to an unforeseen level of mortality (e.g. climate changes, an unanticipated epidemic, etc.).

- Enlargement effects: Closing the gap, reducing premature mortality. Baseline for monitoring health evolution following enlargement.

- Eurostat has developed the European Short list of 65 causes of death as a European reference. DG SANCO has supported projects for improvement of certification procedures (e-death), some specific collection causes (e.g. trauma) or the situation in the new Member States. Projects are encouraged to look at morbidity and mortality data together producing like this an important added value.
Recommendations from the MMWP on major and chronic diseases

- To put, as soon as possible, into operation the ECHI short list of indicators with collection of related data

- To develop the technical scientific work on health indicators in the areas not yet covered
- To improve the existing indicators definitions, when necessary

- To support the improvement of dissemination and knowledge on existing EU morbidity inventories. To update and expand the European Union Morbidity Inventory Project (EUMIP)

- To create an inventory database giving a special attention to sources on information on primary care (GP’s databases, Primary Units and others) and to explore the feasibility of inventorying potential sources of data in the residential and nursing homes care sector

- To support orienting DG SANCO resources for a real implementation of information in a usable way in the statistical field on the basis of a combination of existing sources (or developing sources when necessary) and complementing this implementation with the support to projects collecting the necessary meta-information
Recommendations from the MMWP

- To support the DG SANCO proposals to implement in the web site the ‘Morbidity / Diseases sheets’ for major diseases;

- To encourage participants to present proposals for the major groups of diseases not covered by HMP or PHP projects and developed in the Work Plan 2005;

- To support the improvement of existing networks and databases in the field of Rare Diseases;

- Projects are encouraged to look at morbidity and mortality data together producing like this an important added value;

- To start activities for analysis of specific consequences of events leading to an unforeseen level of mortality.
Operating the recommendations from the MMWP

- Task Force MCD (Major and Chronic Diseases)
- Sub-groups from the TF MCD
- Task Force RD (Rare Diseases)
- Workshop European Health Survey System (acting as Steering Committee since 2005)